

Supporting Real Choice for Nebraskans

"What Must I Do Differently?"

Services Coordination Training

Kearney & Omaha, Nebraska
January 14 & 15, 2004

Summary of Issues

Background

The Real Choice Project is designed to enhance the state's capacity to offer person-centered and consumer-directed services to individuals who receive aging services, and children or adults with developmental disabilities, physical disabilities, behavioral health or medically complex problems. A major element involves assisting the Services Coordinators and Community Support Workers as they seek to assist people with disabilities. Services Coordinators and Community Support Workers are already working in person-centered systems and offering consumers the opportunity to take more control of their lives. However, it is recognized that with appropriate support, these professionals will be able to continue to improve on their ability to assist people with disabilities as they pursue those personal outcomes that are of value to them. This Services Coordination Training is the first of a series of training and continuous improvement activities that were developed as part of the Real Choice Grant.

Services Coordinators who work in Aging and Disabilities, Developmental Disabilities, and the Early Development Network and Community Support Workers working in Behavioral Health Services were invited to participate in this Real Choice training. Approximately 250 Services Coordinators and Community Support Workers and supervisors attended the training.

Training Outcomes

Knowing that the Services Coordinators and Community Support Workers had been working in a person-centered system for years, the training objectives or outcomes were designed to inform them of the objectives of the Real Choice initiative and to offer opportunity to explore ways to improve their current competencies to maximize how they could support people with disabilities. The training objectives included:

- Provide a basic understanding of the Real Choice initiative.
- Reaffirm definitions of person-centered supports and services and consumer-directed services and provide some understanding of what is happening in other states relative to these two approaches.
- Identify those ways that becoming "more person-centered" or "more consumer-directed" may be different than how Services Coordinators and Community Support Workers now do their job.
- Identify those "burning issues" that must be addressed for the Real Choice initiative to

- be truly successful in assisting Services Coordinators to be able to deliver a more person-centered or more consumer-directed set of outcomes for people with disabilities.
- Create an impetus for the development of cross-system collaboration and networking at the regional level in support of all Services Coordinators and Community Supports Coordinators efforts to create broader, more person-centered opportunities for people with disabilities.

This report will summarize the work of Services Coordinators and Community Support workers at the Kearney and Omaha training sessions as they identified as pivotal strategies to their being able to become more person-centered or consumer-directed, including what could be done to create or improve on regional collaboration and networking.

Real Choice & Outcomes for Consumers

The training participants spent time discussing the possible outcomes that consumers may realize as the focus on person-centered and consumer-directed services is broadened and enhanced. They included the following:

Choice -People will have more choice and there will be more follow up on these choices. These choices may result in services that “wrap around” the person more effectively.

Consumer Satisfaction -A streamlined bureaucracy that gives them supports, greater independence and control over their lives and services that are more tailored to their needs and interests should result in a higher number of people being satisfied with their life.

Cross-Disability Outcomes -People with dual disabilities (e.g., developmental disabilities and behavioral health) will have access to services that will be across disability and non-territorial. These choices will result in more customized services because they will be based on a better understanding of the individual and his/her needs.

Better System of Coordination - It will bring in more types of providers and access to providers (shared providers). It will help identify gaps and address them. It will help transition consumers from adult to aging services as well as increase efficiency across the system. This better coordination should also lead to shorter lead times for getting access to services.

More Informed Choice -There will be better education and more information available on resources and providers. This will result in better informed decisions.

More Community Support - This should result in more community awareness and inclusion, which should lead to a more positive relationship between people with disabilities and their communities.

Improved Quality of Life -The person with a disability should notice a number of improvements in his or her daily life:

- People will be encouraged to dream again and get support to help them make those dreams a reality - within some limitations
- People will know their options better and be able to make better choices
- A person's choice or interest should now drive the discussion, giving them more control over the outcome of those discussions.
- They should have fewer crises because better information and more effective planning should result.
- Less duplication (multiple people asking the same question).

- More efficient process for planning and decision-making and better use of their time.
- Fewer phone calls.
- Broader knowledge base of resource.
- A more user- or family-friendly approach - including culture competency/sensitivity.
- Better options based on increased networking with other professionals involved in the person's life.
- An increase in consumer satisfaction (and the checking on consumer satisfaction).

Real Choice & Outcomes for Services Coordinators and Community Support Workers

The training participants spent time discussing the potential outcomes for themselves. With a broadened capacity to be person-centered and consumer-directed, they listed the following possible outcomes:

- They will become more consumer-focused and less service-directed.
- They will be better able to communicate with people with disabilities and their families, better facilitate the consumer's desired outcomes and take professional pride in these outcomes.
- They should become better at problem-solving and advocacy and spend less of their time saying "no".
- They should become more flexible in thought and action, looking for the creative solution rather than just offering a person with a disability a menu of options.
- Their time should be better utilized because there will be less duplication and greater efficiency in matching consumer decisions with services.
- They will have better knowledge of all the multi-disciplinary programs, HHSS resources, and community resources.
- They should have more time to work with people with disabilities because there will be less duplication or redundancy in paperwork and/or tasks.
- They will be more effective in working with people with disabilities because they will have better listening skills and a greater breadth of knowledge about the supports and services that may match up with a person's needs.
- They may like their job better because they will be expected to advocate for people with disabilities more than they are encouraged to do now.
- Their job satisfaction should increase because they should be feeling more successful at matching consumer desires and needs with resources in the community - even if more funding isn't available.
- They will know a lot more of their professional colleagues in the different state agencies, regional offices and community agencies and the services they offer.
- They should be able to rely on a network that is developed specifically for their information sharing.
- They should all be working from the same, consistent interpretation of program offerings and related regulations or policies.
- Their job should be easier because they will be able to rely more on supervisors and the system to "get their back" if they are thinking outside the box.

Burning Issues

Between the two sessions, an extensive list of important issues was generated. Nebraska

Health and Human Services System (HSSS) made a commitment to the training participants that it would summarize those issues and, over the course of the Real Choice Grant, work to address all that were within its scope of responsibility. It made a further commitment to work collaboratively with other agencies if an issue was not directly within its scope of responsibility.

PLEASE NOTE: The following is a summary of the issues that were raised by the Services Coordinators and Community Support Workers and discussed during the training. All items listed below were raised by them. No judgments were made regarding the accuracy or the comprehensiveness of the list of issues or their content. It is assumed that future dialogue will provide the opportunity to allow all facets of the issue to be articulated and verified.

People Need to Know the System is Changing

Changing a system requires that the “customers”, the people with disabilities and their families, understand that the opportunities they will be offered will change. It was clear from the discussion that Services Coordinators and Community Support Workers had done some of the work on this issue over the past few years. However, if there was going to be a major and concerted commitment to doing even more an understanding of Real Choice had to be obtained. Issues that would be important here, as identified in the meetings, include:

- Families that now feel overwhelmed need to be comfortable that they will have appropriate support as they are asked to take even more responsibility for decisions.
- Families, guardians, and communities need to understand and accept people with disabilities have a right to choice and to take responsibility for life decisions (they need to understand the person-centered and consumer-directed philosophies of the Real Choice Initiative).

While there was general agreement that many people with disabilities and families would respond positively to a stronger focus on person-centered and consumer-directed services, it was clear that some families would not. This was characterized in the following issues:

- Family are at times apathetic and lack interest in helping develop a persons’ goals or potential.
- There are times when families appear unwilling to assume responsibility for their loved one, even though they are their guardian.
- Often the family’s desires or interests are in conflict with those articulated (verbally or non-verbally) by the person with the disability.

Services Coordinator and Community Support Workers Role Changes

Some participants of the training felt that to become more person-centered or consumer-directed, their roles would need to change in ways that could be significant. This was clear in their discussion of what it would be like to be “responsible to” rather than “responsible for” people with disabilities and the life-decisions they make. Issues raised in these discussions include:

- We need to dare to dream, be active listeners, and continually challenge ourselves to be creative and focus on the positive.
- The person with the disability needs to be seen as the leader in the planning process and meetings with the Services Coordinator or Community Support Workers taking more of supportive role.
- We need to make sure that we are supporting independence and not dependence on us.

- We need to evaluate how much services coordination or community support coordination each person needs, some need more than others.
- We need to be more creative.
- Services Coordinators and Community Support Workers need to look at the total family and what they need to function, rather than providing fragmented services based on diagnosis or label.
- We need to be sure that we have the right attitude and approach to our relationships with people with disabilities and families:
 - Understand and be sensitive to individual cultures.
 - Families without the skills are really lost in the desert.
 - Elderly may not have parents/families that can step in to advocate and they may tend to be more passive and differential. May be grieving over losses.
 - Be active listeners.
 - Let people have dignity.
- This changes the way that plans are developed and approved.
- HSS needs to demonstrate support for the Services Coordinator and Community Support Workers Coordinator commitment to become more person-centered and consumer-directed by guaranteeing the longevity and continuity of Real Choice.
- The focus of services coordination and community support coordination needs to clearly be empowering and not enabling.
- Part of empowering a person with disabilities is helping them realize that the choices they make are not open-ended, that funding may be limited, and that there are checks and balances that need to be addressed - especially where a potential for concerns related to a person's health and welfare exist.
- A person with disabilities should not be categorized or labeled (i.e., developmentally disabled or aging) because that may limit the options considered - many people can benefit from supports or services available from other systems or from the community in general.
- It may take more diligence and energy to help people with disabilities and families be comfortable enough to take advantage of new, different or more creative supports or services.
- New approaches will be needed to work more effectively with people who have cognitive (judgment impairments) or communication limitations in order to make sure that they have as much control over decision making as possible.
- Services Coordinators and Community Support Workers will need to separate working with people with disabilities and families to create a life plan from their role as "gatekeeper" in deciding how to find the resources to help them implement the plan. More emphasis will have to be placed on finding resources that are either outside the Services Coordinator's or Community Support Workers own system (i.e., available through funding from other agencies) or which do not include publicly funded resources (i.e., either private resources or natural resources) - Lack of funding is no excuse for lack of service. Use community resources, be creative, assist client to be successful in their choices.
- Creative solutions will need to be emphasized when existing policies seem to thwart a choice that a person with a disability wants to make (including confirming that the policy exists and should be interpreted as an obstacle).
- It will be helpful to look to colleagues in other agencies when a person with a disability has an issue that may be within the "core competency" of another agency (i.e., if a person who is aging is having difficulty with life skills that a person with a physical disability may experience).
- The focus should be on accessing the appropriate support or service, not protecting one's turf.
- The more person-centered and consumer-directed, the more there should be a focus on their progress, to make sure that their decisions are working and that any consequences that may arise are properly handled.

- There needs to be a realization that productivity in a more person-centered approach cannot be paper driven or defined simply – offering people choice takes more time.
- There may be more of an emphasis on getting all the providers, involved in a person's life, better coordinated - especially when planning is being done.
- Planning and decision-making may need to be more “pro-active” to make sure that Services Coordination and Community Support Coordination is not just reactive.
- A premium is being placed on flexibility and creativity across the board.
- A premium is being placed on helping a person make decisions, not making them on his or her behalf.
- There is an increased focus on seeking possible simple answers that may exist to meet a person's specific need or support or service (i.e., if a device is needed can it be something that exist for anyone, without it being a “special” or “medical” device?).

People Need Information

It was clear that in order to support people with disabilities as they make informed decisions that Services Coordinators and Community Support Workers needed to have easy access to a broad range of information about supports and services available within a community and how to help people access them. Related concerns that need to be addressed include:

- A lack of concrete knowledge about what is offered in each community and how to find out what is offered.
- There needs to be a consistent and effective means or method of getting resource information to families and Services Coordinators or Community Support Workers (i.e., NRRS, Answers 4 Families.org, etc.).
- As resource directories or information is gathered an organized effort should be made to ensure that it is the broadest set of information about community resources possible - not just those that are within any traditional service system (i.e., make sure it is “cross-disability” and includes “generic” community resources as well as those that are “specialized”.
- The State should have a consistent, up-to-date, and user-friendly means or method of getting this information into the hands of people with disabilities, their families and the professionals who work with them.

Services Coordinators and Community Support Workers Will Need Tools

In order to be successful at becoming even more person-centered or consumer-directed, Services Coordinators and Community Support Workers identified an initial list of tools that they thought would help them be successful.

- Consumer, family and provider training on Real Choice and consumer decision-making are needed.
- There should be an assessment tool that identifies a person's dreams and helps translate that into a plan.
- There should be training on how to become more flexible and more of a problem-solver, given that there are no changes in regulations or policy that are anticipated soon.
- Interpreters should be available when communication limitations require them.
- There needs to be strong, supportive supervisory back-up for Services Coordinators and Community Support Workers who are “thinking outside the box”.
- There needs to be strong supervisory mentoring or coaching as Services Coordinators or Community Support Workers try to become more flexible and more of a “problem solver”.
- Resource directories need to be made available locally.

- Being person-centered and supportive of consumer decision-making requires more time than workloads currently allow (in all systems except the Early Development System). Workload needs to be examined with an eye towards making more time available for Services Coordinators and Community Support Workers to work directly with people with disabilities or their families and organizing access to a broader variety of supports and services.
- There needs to be some consistent guidance on what may be acceptable or unacceptable risks for people to choose to take.
- The system needs to provide more tools for Services Coordinators and Community Support Workers to help people stay in their homes (or placements) even when a person's personal situation, physical health or emotional well-being present challenges, providing it doesn't affect a person's health and welfare.
- There needs to be cross-training to help Services Coordinators and Community Support Workers know about other systems.
- Services Coordinators and Community Support Workers should have access to effective technology to support their work (i.e., laptops, Internet access, list-serves, 800-numbers, etc.).
- The system needs to create multiple and sustained vehicles that allow Services Coordinators and Community Support Workers to interact with other agencies and community systems to make sure their working knowledge is accurate and up-to-date.

The Provider Community Will Need To Respond

System change initiatives such as the Real Choice Initiative can only be successful to the extent that the entire system becomes more person-centered and collaborative. Discussions held as part of the training indicates that the provider community will, in some measure, have to change how it does business for this to work. Included are the following ideas for how provider behavior may need to change:

- Providers need to become more flexible in how they respond to a person's needs and/or choices, being willing to modify what they are offering more than forcing people to fit into existing service structures.
- Providers need to broaden the supports and services they offer.
- Providers need to be willing to hook people up with community supports rather than expect HSS to always pay them for everything in a person's plan.
- Providers have to take more responsibility for making things happen than waiting for families to accept as much of that responsibility as they do now.
- The system needs to develop or include a broader range of providers, especially to ensure that there are different opportunities for people.
- The system needs to do a better job of ensuring quality among all providers and making sure that people with disabilities have alternatives when a provider is not delivering a quality service.
- Incentives should be created for providers that are truly supportive of person-centered and consumer-directed services.

Obstacles that Need to Be Dealt With

Access to Services from More than One State System - Services Coordinators and Community Support Workers need to be able to access services and resources from different state systems for an individual, since not all systems offer the same services and supports (i.e., the lack of environmental modifications in the DD waiver).

- Support from All State Systems* - Although Real Choice focuses only on HSS systems, there is a need for better collaboration and support from other systems (e.g., Voc Rehab).
- Medicaid Eligibility* - The system needs to be more efficient at enrolling people in Medicaid and maintaining or managing their continued enrollment to enable them to stay on waivers.
- Intake* - There is an opportunity to streamline the intake process and paperwork and make it more user-friendly. It may also be valuable to take a “cross-agency” or “universal” approach to intake to reduce redundancy.
- Caseloads* - Caseloads need to be evaluated to see if there is a way to better organize them (to allow for more efficient use of Services Coordinator or Community Support Workers time), including reducing paperwork and considering the possibility of organizing or categorizing caseloads based on individual need. There may also be a need to adjust caseloads in rural areas where driving (windshield time) takes much longer.
- Adequacy of Funding* - It was clear that the choices people with disabilities will ultimately make are based on the available funding, this may constrain choice.
- Flexible Funding* - In addition to being able to access resources from more than one system, the funding available in any part of the HSS system should be allowed to be used in the most flexible way possible, to support individual choices that do not fit neatly into existing service definitions.
- Regional Center Closures* - The impact of these closures on Services Coordination workloads may run counter to the objectives of Real Choice.
- System Structure* - HSS needs to find ways to make waiver rules, provider guidelines and diagnostic regulations more flexible to support what Services Coordinators and Community Support Workers efforts to be more person-centered and consumer-directed. At the same time, HSS should look to transfer those good parts that exist in some systems to all systems.
- School to Adult Transition* - It needs to be more flexible, it is too rigid and people are falling through the cracks.
- People with Medical Needs* - The system does not currently offer many options for people who have medical issues but who want to remain at home. Capacity and strategies for helping them need to be developed.
- People and/or Families Hiring Staff* - There needs to be effective procedures and guidelines for consumers or families who wish to hire and manage their own staff. The system needs to re-evaluate current policy to make sure that consumers and families are able to hire the right people for their needs and situation.
- Stability of Staff and Continuity of Services* - The system needs to deal with high staff turnover and the disruption this creates in people’s lives and the quality of services that are provided.
- Choice in Rural Areas* - The system needs to develop a clear plan to address choice in areas that do not have multiple providers available.
- Acceptable Risk* - Although the system has fairly clear guidelines and procedures related to identifying risk and managing risk, additional guidance is needed because the more consumer-directed the decision-making process, the less control that a Services Coordinator or Community Support Coordinator has on the outcome of the decision-making process. There should also be guidance and training to help staff refrain from imposing their values (re: risk) on consumer decisions - unless

a threat to health and safety can be demonstrated.

System Guidelines - HSS has to re-evaluate its system structure (legislature, regulations, policy, waivers, operational guidelines, QA system, etc.) to make sure that they are not only compatible with person-centered services and consumer-directed services, but supportive of them as well.